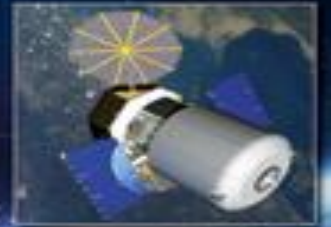


International Data Sharing: Tools and Rules

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What do you mean by Data Sharing

- Data can be defined as raw or processed results from a test conducted on a subject in flight or an analog. It can also include biological samples themselves
- Data sharing is the use of the human biomedical information originally generated by medical, operational, or another research activity to support a different investigation
- Data sharing can occur during the strategic, tactical, or implementation timeframe
- Data sharing can also occur after an investigation or relevant activity is completed
- The Multilateral Human Research Panel for Exploration (MHRPE) Data Sharing Principles, signed by the ISS Partners, provides guidelines for the intent of international data sharing
- Collaborating investigators and their sponsoring agencies have the responsibility of identifying the data to be shared, and its delivery and use parameters within a Data Sharing Agreement*



* Data Sharing Agreement Templates and Guidelines can be obtained from the MHRPE (Jon McFather – Executive Secretary jon.c.mcfather@nasa.gov)

Why International Data Sharing

- ISS and analog resources are limited
- Sharing enables us to get the data we need faster to gain the knowledge we seek to resolve the risks we have for human space flight
- Biomedical research programs across the partners often address similar questions
- Sharing reduces the burden on the subjects to do duplicative studies or tests
- Two (or more) brains are better than one
- Sharing allows us to use data previously collected to support new questions
- When new analytical tools come on-line, we can use already available data



How Do We Share Data

- Joint investigations
 - Investigation has multiples PIs and can be from multiple countries. Data and results are shared as mutually agreed upon by all investigators
- Desire by PIs to share data collected from another investigation
 - Scientific collaboration- PIs agree that data (raw or analyzed) will be shared among them according to a specific experiment-to-experiment agreement (Data Sharing Agreement)
 - Logistical collaboration – During simultaneous implementation, such as on an ISS increment, PIs needing to perform the same test, or take the same (or similar) samples agree on one entity collecting the data, and then sharing it.



Data Sharing Tools

- Data Sharing Agreements
 - Data shared between PIs of cooperating agencies
 - Can be facilitated through agents of the PIs
- Data Sharing Plans- tactical (ISS increment or analog campaign)
- Life Sciences Data Warehouse (LSDW)
 - International Data Sharing Portal for actual data Exchange
 - Available to authorized investigators
- Archives
 - NASA- LDSA <http://i54.tinypic.com/j5f1nm.jpg>
 - Other ISS agency archives still to be defined
- Data sharing Agreements – PI to PI



Core International Data Sharing Rules & Principles



- All data sharing between investigations requires an agreement
- Data sharing between investigations requires approval of ethics boards and the informed consent of the subjects BEFORE data sharing occurs

- Data sharing across partners should be endorsed by their respective agencies
- Data sharing among partners must follow privacy and confidentiality rules of the countries involved
- When possible, first clearly identify all attributes *necessary* for your investigation when proposed (requirements); don't anticipate any data will be collected by others (i.e. medical data) and available



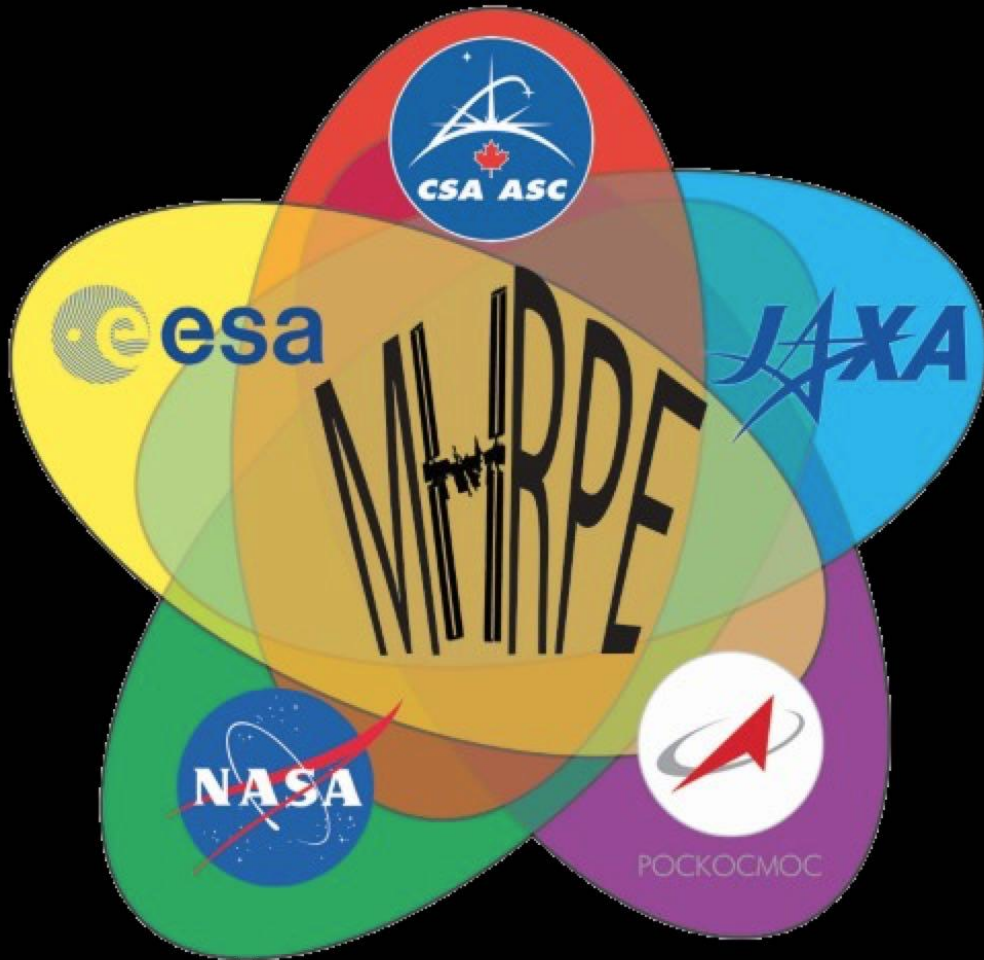


Rules for Handling Data

- All data collected on subjects (astronauts, cosmonauts, ground subjects) must be treated as confidential
- Informed consent is required for all data sharing outside a joint investigation
- New rules in place for NASA teams taking IT hardware to foreign countries
 - IT equipment includes laptops, iPads, smart phones etc.
 - IT equipment with biomedical data must be under NASA control at all times
 - IT equipment used as part of science data collection systems must be approved in an IT plan with risk mitigation plans approved before shipment out of the country
- Non-NASA investigators collecting data on NASA affiliated subjects should implement similar security measures on IT devices
- Recent hacking incidents remind us that no data or system is immune

Multilateral Human Research Panel for Exploration

The MHRPE strives to reach consensus on common requirements for human research, including research protocols, hardware and data sharing, and increased efficiency of use of ISS crewmember subjects toward common exploration goals.



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Thank You!



Questions?